



3RD SCIENTIFIC CONGRESS

MAY 22-24, 2018 | TORONTO, CANADA

SUMMARY REPORT

PROGRESSIVE MS — MAKING A DIFFERENCE
THROUGH REHABILITATION & SYMPTOM MANAGEMENT

INTERNATIONAL
PROGRESSIVE MS ALLIANCE

CONNECT TO END PROGRESSIVE MS



International Progressive MS Alliance Convenes Stakeholders to Focus on Symptoms and Rehabilitation at Third Scientific Congress

It's rare to have people living with MS, family members/caregivers, physical and occupational therapists, brain researchers, psychiatrists and neurologists all in one room, sharing their points of view. That's what happened when more than 225 researchers and supporters from 16 countries gathered in Toronto in May for the International Progressive MS Alliance's Third Scientific Congress, "Making a Difference Through Rehabilitation & Symptom Management." The result was a new perspective and resolve on urgent next steps to find solutions that will improve quality of life for people living with progressive MS.

Experts provided updates on approaches to restoring function and enhancing brain rewiring and addressing MS symptoms, including learnings from other disorders. Participants also discussed ways research is improved when study designs incorporate the perspective of the person living with the disorder being investigated. Rehabilitation and symptom management research is beginning to be translated into practice, but there is more work to do to find the best ways of enhancing well-being for people with progressive MS. This goal is one of three strategic priorities for future Alliance activities.

"This Congress integrates multiple fields and the most promising areas," said Alliance Scientific Steering Committee Chair Professor Alan Thompson (University College London, UK). "Bringing everyone together is critical, and there is no doubt that these findings will influence the field and encourage new research on rehabilitation."

The conference, co-chaired by Profs. Anthony Feinstein (University of Toronto, CA) and Xavier Montalban (University of Toronto, CA), was sponsored by the Progressive MS Alliance, with additional support from the European Committee for Treatment and Research in MS to facilitate the attendance of young scientists.

PROMOTING RECOVERY

LESSONS FROM STROKE

Prof. Nick Ward (University College London, UK) and others described rehabilitation studies in people who had experienced stroke, in which blood flow to an area of the brain is cut off and cells die. Stroke affects millions of people and consequently more research has been done on the benefits of rehabilitation in stroke than in other conditions like MS.

Dr. Michelle Ploughman (University of Newfoundland, CA) noted results of a study in people with stroke suggesting that engaging in aerobic exercise before receiving cognitive training improved recovery better than either could alone, apparently by increasing brain plasticity. This approach is being applied in a new clinical trial in progressive MS, which combines aerobic exercise with cognitive rehabilitation in a large international study.

Some findings that may be applied to MS include understanding the person's impairment and site of damage to customize the rehabilitation plan and making the plan relevant to daily life. Stroke studies suggest rehabilitation needs to be intensive and patients need to be actively engaged to gain sustained improvement. For example, at University College London, the stroke program involves 90 hours of rehabilitation over a three-week period. There also seems to be a critical period after injury when rehabilitation can maximize recovery. It's not clear yet when the "window of opportunity" for optimal improvement might be in a chronic disease like MS.



Dr. Michelle Ploughman, University of Newfoundland (CA) presents on insights from stroke research and applications to progressive MS.

EXERCISE — WHEN, WHAT, HOW MUCH?

Prof. Ulrik Dalgas (Aarhus University, DK) discussed how exercise and physical activity are thought to activate nearly every cell and system in the body and may even rebuild brain connections. Conference attendees noted that there have been many small studies suggesting a wide variety of benefits from exercise in people with MS, but because of the small size and design of those studies, it remains somewhat difficult to know exactly how much and what kind of exercise will have the most benefit for a person living with MS.



“We are unreasonable. Unreasonable people go about seeing the world differently and trying to make it a better place.”

– Dr. Alexis Donnelly, Member, Alliance Scientific Steering Committee



IMPROVING COGNITION

Dr. James Sumowski (Mt. Sinai School of Medicine, US) and Prof. John DeLuca (Kessler Rehabilitation Institute, US) discussed the prevalence of cognitive issues (such as slowed processing of information and memory problems) and the benefits of rehabilitation strategies. However, they emphasized the need for more and better designed clinical trials of treatments to address cognitive issues in people with progressive MS. Strategies are emerging that are helpful for specific cognitive problems, but simply doing commercially available “mind games” may not be sufficient to improve function. Several speakers (Profs. Stefan Gold, Charité – Universitätsmedizin Berlin, and Rob Motl, University of Alabama, US) noted that aerobic exercise together with cognitive training improved brain plasticity and enhanced recovery.

BRAIN STIMULATION

Mounting evidence suggests that besides aerobic exercise, there may be other ways to promote brain plasticity—the functional or structural reorganization of nerve connections. In that primed state, the brain may be more receptive to the benefits of rehabilitation. Several congress participants including Drs. Letizia Leocani (San Raffaele Hospital, IT) and Marco Bove (University of Genoa, IT)

described potential benefits of specifically targeting brain networks to promote recovery using noninvasive approaches such as transcranial magnetic stimulation or transcranial direct current stimulation.

Dr. Jonathan Downar (University Health Network, CA) described recent progress in mapping abnormalities in specific areas and networks of the brain and their links to specific types of mental health disorders. This knowledge has improved the use of magnetic stimulation targeted to specific brain regions. The goal is to individualize where stimulation is provided, tailoring treatment to individual needs. Although this isn’t used yet for treating mood disorders in MS, it emphasizes the need for deeper understanding of the structural causes of specific MS symptoms so that treatments can be better personalized.

There is some evidence that this type of stimulation has potential to treat depression, anxiety, fatigue and cognitive issues, and it has the potential for being done at home. These techniques may also be combined with rehabilitation interventions. Dr. Leocani also discussed the concept of “prehabilitation”—the idea that if it can be predicted that an individual is likely to lose function in the legs or arms in the future, there might be benefit to strengthening that function before the loss occurs.

Photo, left: L to R – Gemma Donnelly Cox, Dr. Alexis Donnelly and Cory Turner discuss the Alliance’s strategic research priorities and future focus of work. Photo, right: L to R – Prof. Alan Thompson, Prof. David Miller, Bernadette Porter, MBE, Dr. Patrick Freund and Prof. Nick Ward discuss the sessions from the day.

ENHANCING WELLBEING

Prof. Paul Matthews (Imperial College, UK) discussed the complexity of factors that influence a person's individual biology and experience of MS and wellness. He noted that modifying symptoms with rehabilitation can change the brain in beneficial ways and stimulate the genesis of brain cells. "Perhaps we should rethink neuro-rehabilitation as "neuro-restoration," he said.

IMPACTS OF OTHER HEALTH ISSUES

Prof. Ruth Ann Marrie (University of Manitoba, CA) described the impacts of "comorbidities"—other health issues an individual may have along with MS. Studies suggest comorbidities are often present at the initial diagnosis of MS, and the physical ones increase with aging. The most common comorbidities are depression, high blood pressure, lung disease and anxiety.

She noted that vascular comorbidities like high blood pressure and diabetes may accelerate MS progression, and depression has been associated with cognitive problems. Prof. Marrie suggested the possibility that addressing comorbidities may reduce MS progression and symptoms and improve quality of life, and that testing this notion in clinical trials is an important priority.



Prof. Francisco Quintana, Brigham and Women's College, Harvard Medical College (USA) asks a question of the panel.

ADDRESSING SYMPTOMS IS CRITICAL

Presenters showed evidence that many troublesome symptoms can be improved right now, but there are many unanswered questions that need further research. For example, Prof. Marcia Finlayson (Queens University, CA) described a self-management approach for fatigue. This involves an individualized mix of training in problem solving, prioritizing, energy management and changing the way people think so that they take charge of the issue. The approach requires a professional

facilitator with a mental health background, which creates challenges to delivering the program broadly. She also mentioned a new large-scale clinical trial getting underway that will compare different ways of delivering fatigue management programs for MS.

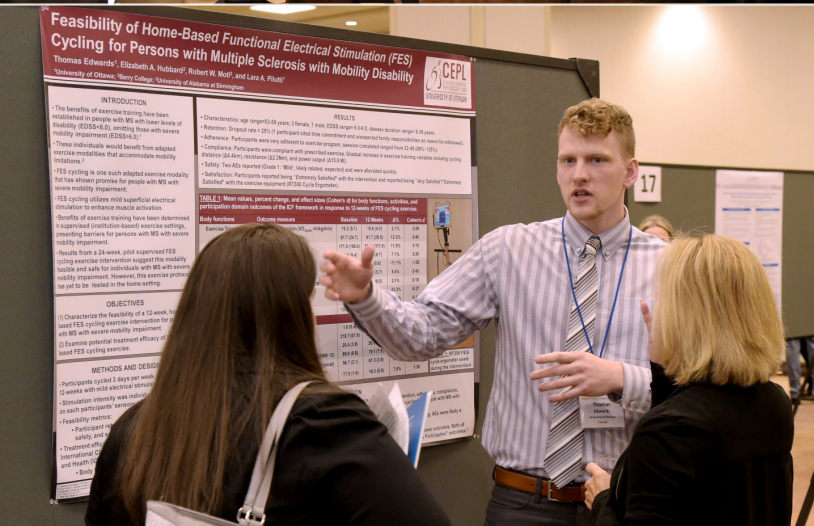
Another example of the urgent need to address symptoms came from nurse consultant Bernadette Porter (National Hospital for Neurology and Neurosurgery, UK), who identified a healthcare solution to address the tremendous number of hospitalizations needed by people with MS whose urinary tract infections went out of control because of delays in lab work and treatment.

“We want to know: Are people with MS having better lives? That’s how we will know we are making progress.”

– Cyndi Zagieboylo, Chair, Progressive MS Alliance Executive Committee and National MS Society President & CEO (US)

PROMISE OF TECHNOLOGY

Several speakers discussed the potential for technology to assist with rehabilitation and daily tasks. Dr. Shane Saunderson (University of Toronto, CA) has been developing socially engaging robots that may one day help improve quality of life for people and their caregivers by taking on simple chores of daily living. For example, the team programmed a robot to interact with residents and facilitate a Bingo game in a group home.



IMPROVING RESEARCH QUALITY

WHO? HOW? WHEN? DOSAGE? CAN REHABILITATION CHANGE THE COURSE OF MS?

Many congress participants cited the need for high quality rehabilitation studies in progressive MS to address gaps in knowledge. “We need to be interdisciplinary and combine interventions,” said Prof. Peter Feys (Hasselt University, BE). Keynote speaker Dr. Alison Cernich (National Center for Medical Rehabilitation Research, NIH, US) commented, “If we know what is effective and when to do it, it creates a better basis for advocating for insurance coverage.”

INCORPORATING PERSPECTIVES OF PERSONS WITH MS

Drs. Giampaolo Brichetto (Italian MS Society, IT) and Robert McBurney (Accelerated Cure Project for MS, US) discussed an ongoing research initiative by the MS International Federation to develop consistent “patient reported outcomes” (PROs) that can be used to determine the impacts of a given experimental therapy on people’s daily lives and functions. Dr. Brichetto noted that PROs can also help predict future progression. Ideally future clinical trials of all types of interventions will use standardized PROs to enrich understanding of how the intervention contributes to quality of life from the point of view of individuals with MS.



Prof. Rob Motl (US), University of Alabama, Dr. Giampaolo Brichetto (IT), Italian MS Society and Prof. Jaume Sastre-Gariga (ES), CEMCAT, discuss priorities for key areas impacting translational strategies in Progressive MS.

During a panel discussion focused on the views of people living with progressive MS, Dr. Alexis Donnelly (Progressive MS Alliance Scientific Steering Committee, IE) noted that some PROs were collected during recent clinical trials, but their results were not reported in the published studies. As a person who lives with progressive MS, he also commented that it would be worthwhile capturing the perspective of caregivers, “the invisible other half,” who may have a different take on the individual’s fatigue, depression or other symptoms.

The Alliance Scientific Steering Committee includes members whose lives are affected by MS. They were part of the evaluation of research applications that led to the funding of three **Collaborative Network Awards**. Steering Committee member Dr. Caroline Sincock (UK), who lives with progressive MS, said that including people with MS during the design of studies can help make sure the research addresses a relevant problem experienced by people living with the disease, and can help make sure on a practical level that research participants will be able to do what's asked of them.

POSTER SESSION ENHANCES INTERACTION

A key component of the congress was the “poster session”—where researchers stood by display boards that depicted the methods and results of a wide variety of rehabilitation studies. This provided opportunities for informal interactions between attendees and free exchange of ideas and plans.

FUTURE STRATEGIC PRIORITIES UNVEILED

During congress activities, Progressive MS Alliance leadership unveiled new Strategic Priorities that will guide future activities and funding. The priorities are:

- Understand progression
- Accelerate clinical trials
- Enhance well-being through rehabilitation and symptom management

Work is getting underway to map out next steps to move these priorities forward. This congress is a first step to discovering the areas that the Alliance should target to enhance well-being. As shown at this congress, noted Prof. Alan Thompson, “Rehabilitation has huge potential.”

“For all of us with accumulated disability, enhancing well-being is so critically important... When I think of the Alliance personally, the Alliance is about a better present and a better future.”

– Cory Turner, volunteer, MS Society of Canada



Dr. Caroline Sincock (right) talks with a researcher during the poster session.



Congress speakers, panelists and organizers.

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The International Progressive MS Alliance is a global initiative that aligns international MS organisations, people with MS, the scientist community and industry from around the world.

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